Focus on Progress

Rhode Island Office of Families Raising Children with Special Health Care Needs (OFRCSHCN)

Deborah Garneau, Director
Office of Families Raising Children with Special Health Care Needs
Division of Family Health, Rhode Island Department of Health
3 Capitol Hill, Room 302 Providence, Rhode Island 02908-5097
Phone: 401-222-5929; Fax: 401-222-1442
Email: Deborah.Garneau@health.ri.gov
Family Health Information Line 1-800-942-7434

Dawn Wardyga, Director
Family Voices at the Rhode Island Parent Information Network
75 Main Street, Pawtucket, Rhode Island 02860
Phone: 401-727-4144; Fax 401-727-4040
Email: FamilyVoices@ripin.org

Snapshot of Rhode Island's Services

The Office of Families Raising Children with Special Health Care Needs (OFRCSHCN) ensures family-centered, community based, integrated systems of services for children & youth with special health care needs (CYSHCN) through infrastructure-building activities, training/technical assistance, and collaboration with families, other state agencies, health plans, and community organizations. **OFRCSHCN** offers:

- **Pediatric Specialty Services** help to coordinate and monitor specialty care for CYSHCN and their families through contract management; preparation of specialty resource guides and interdepartmental administration of RI's care coordination system called Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Re-Evaluation (CEDARR).
- **Family Support** is provided via contracts with Family Voices at the RI Parent Information Network (RIPIN) to recruit, train and support family members for outreach, family support, family-to-family networking and policy development at state and local levels.
- **Parent Partners in the Clinical Setting** employs and strategically places parent partners throughout the service delivery system to ensure access to family-centered services and promote ongoing improvement in the health care system.
- **Medical Home Initiative** sponsors the Pediatric Practice Enhancement Project to provide parent consultants to participant primary care practices to enhance the provision of a coordinated medical home.
- **Disability & Health** (DHP) program promotes health and wellness for people with disabilities, effective transition from adolescent to adult health and disability surveillance.

Progress in Building a System of Care

In Rhode Island, 14.1% or 35,265 children under age 18 have special health needs (National Survey of CYSHCN, 2001). All states are striving to achieve a community-based system of services for all families of children and youth with special health care needs by the year 2010. The table below reflects Rhode Island's progress in achieving a system of care for CYSHCN and compares it to the nation at large.

Snapshot of Rhode Island's Children & Youth with Special Health Needs*

Child Health	Impact on Family	Family-Centered Care	Access to Care	Insurance
18% experienced health conditions that frequently affected their daily activities (23% US).	15% of families experienced financial problems due to their child's health needs (21% US). 11% of families spent more than 11 hours a week providing or coordinating health care for their child (14% US).	31% of families did not consistently receive care that was family-centered (33% US).	13% had one or more unmet needs for specific services (18% US). 17% had problems getting a referral for specialty care (22% US). 10% did not have a usual source of medical care or relied on emergency rooms (9% US).	27% did not have adequate insurance coverage (34% US). 7% did not have insurance at some point in the past year (12% US).

*Child and Adolescent Health Measurement Initiative (2005). *National Survey of Children with Special Health Care Needs 2001*, Data Resource Center on Child and Adolescent Health Web site. Retrieved 8/19/05 from www.cshcndata.org.

State Accomplishments

All 50 states and territories are in the process of achieving six national outcomes CYSHCN, as part of the President's New Freedom Initiative by 2010. Rhode Island hosts an annual parent / professional partnership conference focusing on the 6 core elements highlighted below:

Outcome #1 Families as Decision-Makers and Satisfied: Family Voices at the RI Parent Information Network (RIPIN) as the state's Family-To-Family Health Information and Education Center, provides information, education, advocacy, and peer support to families and professionals concerning raising children and youth with special health care needs. Further, RI employs over 35 parent consultants in clinical settings to ensure family-centered practice and to maintain continuous quality improvement.

Outcome #2 Medical Home: RI implemented a medical home enhancement model that employs trained parent partners in 8 primary care practices and 25 specialty care practices, including the state's largest neonatal intensive care unit and pediatric intensive care unit to link families with community resources through care coordination. The Family Voices Leadership Team addresses systems barriers to coordinated care delivery.

Outcome #3 Adequate Insurance: RI Children's Cabinet is committed to maintaining high insurance rates for all children and especially CYSHCN. Through the Medicaid Consumer Advisory Committee, Health Insurance Advisory Council, and Neighborhood Health Plan of RI's CYSHCN Advisory Committee, CYSHCN and their families have direct input in ensuring adequate insurance.

Outcome #4 Screening: RI's Universal Newborn Screening Program involves screening and follow-up for a growing list of metabolic, endocrine and blood disorders in addition to hearing screening and developmental risk assessment. Results are recorded in the state's KIDSNET System, which offers data query and individual tracking systems to the state's primary and specialty care practices.

Outcome #5 Integrated Community-Based Services: RI's Care Coordination System and the Parent Partners projects provide direct assistance to families raising CYSHCN as they navigate the service delivery system. They also provide systematic feedback to the Family Voices Leadership Team (membership is comprised of parents and leaders from state agencies, health plans, community providers, parent organizations and physician groups) to remedy system barriers to comprehensive, coordinated, family-centered care.

Outcome #6 Transition to Adult Life: The Disability & Health Program (DHP) actively participates in RI's Rhodes to Independence Initiative and the Governor's Transition Council that bring together youth, families and interagency providers to develop a coordinated plan to support successful transition to adult life. DHP is actively surveying and educating pediatric and adult medical providers concerning adolescent health care transition.

Useful Rhode Island Web Sites & Links

- **DOH DFH Homepage:** http://www.health.state.ri.us/family/
- **DHS Child & Family Services:** http://www.dhs.ri.gov/dhs/dserfch.htm
- **Family Voices of Rhode Island:** http://www.familyvoices.org/st/RI.htm
- **Rhode Island Parent Information Network:** http://www.ripin.org/
- **Neighborhood Health Plan of RI:** http://www.nhpri.org/
- **State Data Profile:** http://cshcndata.org/DesktopDefault.aspx?topic=stateprevalence&geo=Rhode%20Island

A Community Snapshot

Parent/professional partnerships are instrumental in helping families access needed services within their communities, as demonstrated by the support services offered to families through the Pediatric Practice Enhancement Project and the Family-to-Family Network. For example, Maria brought her four-year old daughter Anita to her pediatrician at Park Pediatrics, Inc. with concerns about Anita's inability to speak. The physician referred Maria and Anita to Andrea DeJesus, the Park Parent Partner. Ms DeJesus assisted Maria in accessing Child Outreach Screening and a subsequent preschool program. A few months later, Maria reports she is thrilled by these services and Anita's language development in Spanish and English.

A second example involves a young Liberian immigrant, Samuel who was separated from his family and bounced around from friend to friend throughout his school years. As a senior in high school, Samuel was referred by his primary care physician at Thundermidst Health Center in Woonsocket to Patty Gamache, the Thundermist Parent Partner who helped him to access educational testing. Samuel himself requested an evaluation at his high school, this did not occur until Ms Gamache and Samuel's physician requested the testing. Within weeks, the testing was conducted and Samuel was diagnosed with attention deficit/hyperactivity disorder and an Individualized Education Plan (IEP) was written. In addition, Samuel was having trouble with his college applications due to discrepancies related to his birth certificate. Ms Gamache connected him with the International Institute in Providence where he received the help he needed, applied and was accepted to three colleges. Samuel is planning to attend a university in a neighboring state that has learning labs set up for youth who need extra help with organizational skills. In the words of Ms Gamache, Samuel "has overcome a lot on his own and really was eager to follow all the leads that I gave him. He is on the road to really changing his life!"

Another example highlights the family-to-family support system in RI. At six months pregnant, Beth learned that her child would be born with spina bifida. Through the Family-To-Family Network and the Rhode Island Family Voices, Beth was provided with support, resources and a mentoring mother of a 4-year old with the same diagnosis. This has been a meaningful connection for both mothers and a great example of how family-to-family connections make a difference – even prenatally!

Champions for Progress
A Community of Learners
champions@championsforprogress.org

The work reported in this document was supported through a cooperative agreement (#U42MC00241) from the Health Resources and Services Administration, Maternal & Child Health Bureau to the Early Intervention Research Institute at Utah State University.